

RUSSIAN REGISTRY OF PATIENTS WITH TUMORS OF THE HYPOTHALAMIC-PITUITARY REGION (OGGO): OCTOBER 2013 UPDATE FOR ACROMEGALY



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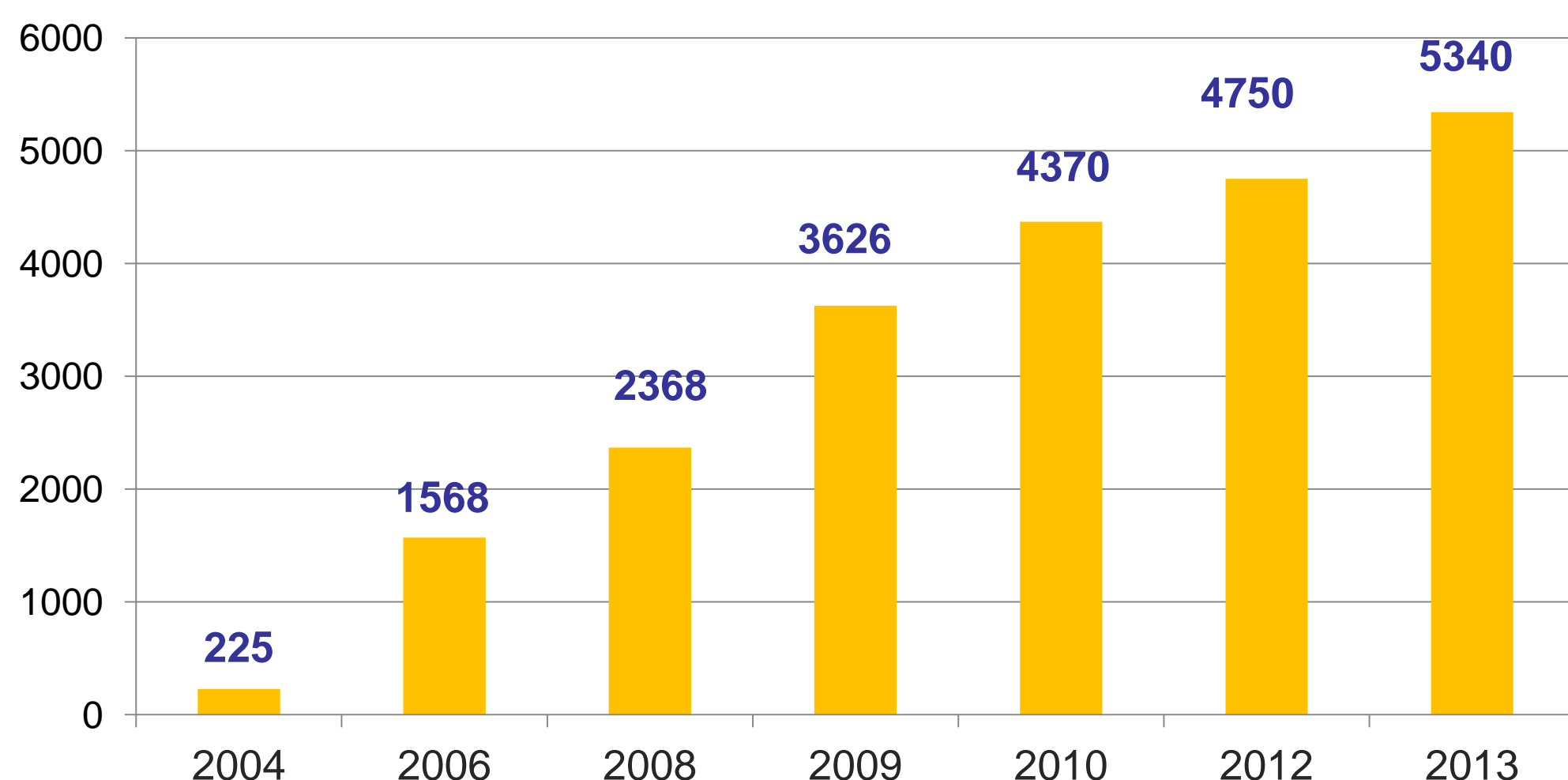
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Introduction

The Russian Registry of patients with tumors of the hypothalamic–pituitary region (OGGO) is a national registry founded in 2004 by Russian society for Endocrinology and Endocrinology Research Centre as a patient registry for acromegaly, in 2006 it was expanded to collect information on all lesions of the hypothalamic–pituitary region, in 2010 the first fully electronic version and in 2013 a new upgraded electronic online version were implemented. At this point the Registry is actively supported by 22 out of 83 regions of Russia, representing about 1/3 of population.

Materials and methods

There are overall 5340 patients registered in the OGGO from 2004 to 2013.

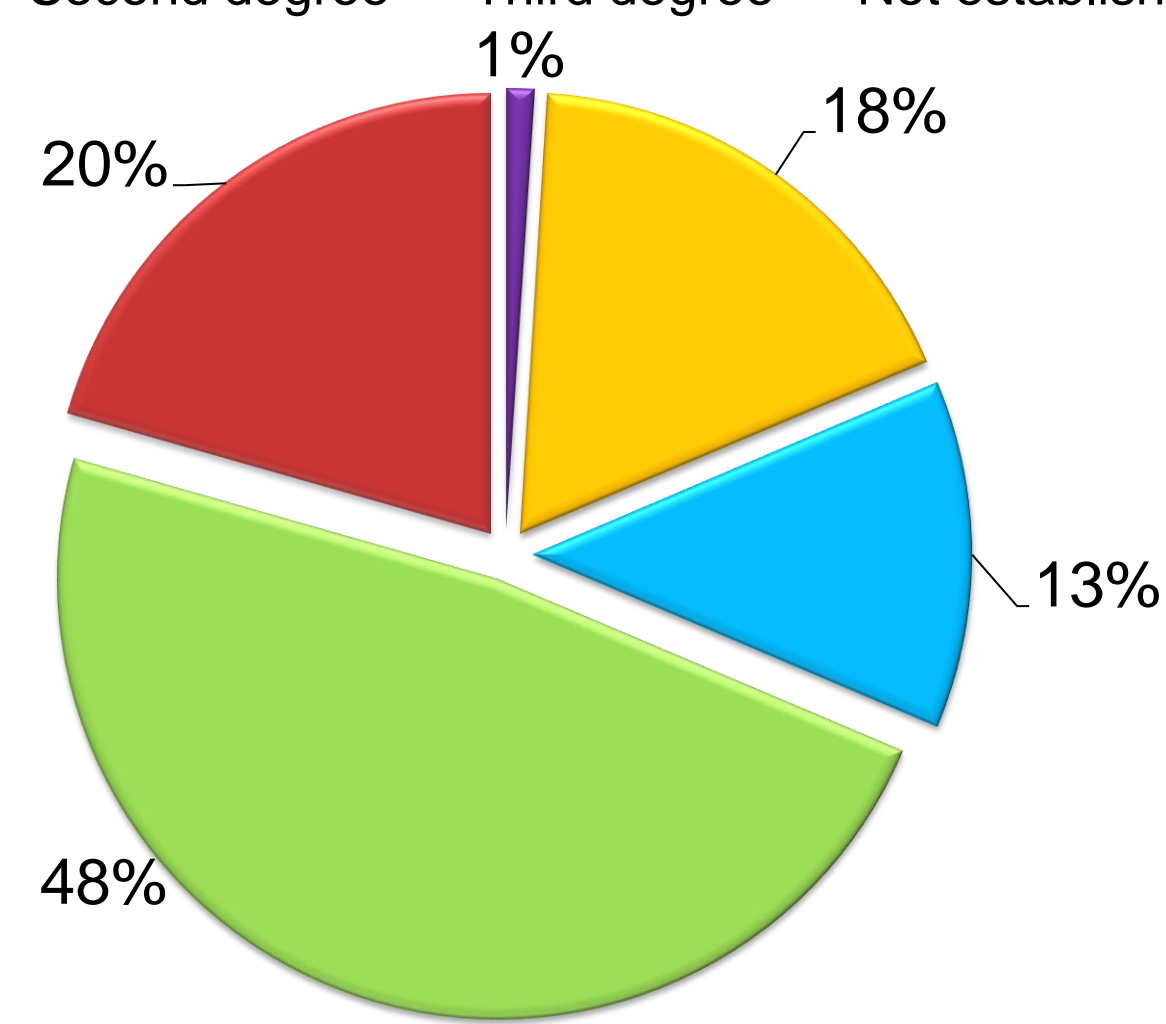


Conclusion

Acromegaly is a highly disabling disease. Our database show low implementation of surgical and specific drug treatment among acromegalic patients.

Physical disabilities in acromegalic patients (n=2943)

■ First degree ■ Second degree ■ Third degree ■ Not established ■ No data



Results

The largest part of registered patients constitutes patients with acromegaly (53%), followed by patients with prolactinomas (26%), inactive pituitary tumors (9%), Cushing's disease (6%), mixed secretion pituitary tumors (4%), and other tumors (2%). Among 2781 patients with acromegaly 72% are women. Peak incidence is between the ages of 40–50 years. 1% of patients have got first (highest) degree of disability, 18% - second degree and 13% - third degree. 57% of acromegalic patients do not have updated disease status, only 6% of patients have remission, 7% partial remission and 30% are in the active state of the disease. Hypopituitarism is present in 9% of patients, visual disturbances in 16% and neurologic complications in 63% (e.g. headaches – 87.5%, carpal tunnel syndrome – 5%, ptosis – 3.7%, vertigo – 2.7%, diplopia – 0.9%). Surgery was performed in 33.1% of patients, 17% received radiation therapy and 49% - drug therapy (octreotide long acting – 28%, lanreotide long acting – 2.6%, bromocriptine – 24%, cabergoline – 5.6%, with about 9% of patients receiving combination therapy of dopamine agonists and somatostatin analogs).